Living with Chronic Graft versus Host Disease

- I am the Staff Social Worker at the National Bone Marrow Transplant LINK, (nbmtLINK). I am also in private practice. I received my Master of Social Work degree from Wayne State University and have spent over 20 years in oncology. The majority of these years where done by leading the support programs for oncology over Providence Hospital and Providence Novi Hospitals. At nbmtLINK, I am available to assist with emotional support, resources, and assisting with supportive programming.

Survivors are our best teachers

- There is no “one size fits all answer” and it is often a highly emotional experience

- “I thought this transplant was supposed to make me better”

- We need to have a realistic view of what coping is. It takes time for the body heal, so it takes time for the soul.

- You have survived a “personal earthquake”, which required an increased tolerance for the unknown as you walk with exhaustion, consistent pressure, grief, loss of identity, relationship changes, loss of control, and cGVHD can cause distressing symptoms that can make you feel discouraged

Living and thriving with cGvHD

- To find how to live the best version of you, making the best of what your body can do, finding ways to cope, minimizing emotional distress, finding ways to reconnect with the world around you, and establishing a renewed sense of meaning and purpose in your life.
- It is walking in balance with persistence, patience, hope and acceptance.
- Attend conferences and network as you look for solutions
- Get nbmtLINK’s cGVHD book

Set Realistic Expectations

- What is your new norm?
- Reclaim areas of importance in your life while allowing for flexibility and creativity
- Understand that everyone that loves you walks this journey with you. You all may cope differently but work together as a team to support each other.
- Know when to ask for help
- Learn to say no

Tips from Jen…

- Jen recommends keeping a list of the gains you make so you have something to reference when you feel discouraged.
- Jen learned how to adapt with the changes she noticed with herself. Walking around the office once an hour and resting her eyes from the computer were important once she was strong enough to return to work. She also modified her time in the office.
- Jen recommends the video, *The New Normal*, made by nbmtLINK.
- Visit our website, www.nbmtlink.org. Jen shares how important it was to see this recovery as a marathon and not a sprint.

Tips from Meredith…

- Discover what time of day your body is at its peak and try to schedule what you need to do during these times
- Allow yourself breaks
- Prioritize
- Break bigger tasks into smaller tasks
- Become your own author in life.
- Discover what brings you meaning, joy and hope

Tips from David

- **Find ways to stimulate your brain** (learn a language, crosswords, etc.**)**
- **Look for positives**
- **Find ways to be social, even on the transplant floor**
- **Exercise**
- **High Quality Foods instead of junk food**
- **When able, get involved (**He helps others going through the journey now**)**
- **Accept life will never be the same, it is different, but increase the quality of life**
- **Fatigue is no joke, get the rest you require and it helps you get more done**
- **Consider counseling**
- **Consider talking with someone who has been through it, peer mentors are available through nbmtLINK**

Tips from Lew…

- He viewed his transplant as a "recall to life"
- He and is wife were a team that had an attitude of "whatever it takes to fight this" together
- A strong support team
- Chose a project to distract himself
- He attends support groups, senior groups, and stays active. His wife and he enjoy walking together and participate with an app, www.charitymiles.org. Large corporations will donate to charities of your choice by the level of walking you do.

Communicating With Your Healthcare Team

- Develop a system to stay organized
- Communicate clearly and honestly with your providers
- Keep a running list of symptoms, health status changes, and new questions and ask how they can be treated
- Be a strong advocate for yourself
- Have a medical coordinator for your care
- Copy other healthcare providers on emails
- Use the whole health care team
- Consider attending conferences
- Don’t give up

You can't stop the waves, but you can learn to surf- Joseph Goldstein

Questions???

At this time you may send us any additional questions and we will do our best to answer as many as we can live. Those that are not able to be answered in today's webinar will be addressed via email.

Upcoming Events

October 21st- Lunch & Learn with the LINK
Mindfulness Matters with Physician Assistant, GeAnne Geraghty and survivor, Peter Thomason

October 29th Webinar on Survivorship with Christina Ferraro, Nurse Practitioner, and social workers Amanda Budai and **Katie Schoeppner**

This program was made possible by the generous support of:

Pharmacyclics

Incyte Corporation

Meredith Cowden Foundation

Special Thanks to Our Esteemed Link Partners

American Society for Blood & Marrow Transplantation (ASBMT), Barbara Ann Karmanos Cancer Institute, Be The Match, Blood and Marrow Transplant Program at Northside Hospital, John Theurer Cancer Center at Hackensack UMC, Blood & Marrow Transplant Program, The Sidney Kimmel Cancer Center at Thomas Jefferson University, Center for International Blood and Marrow Transplant Research (CIBMTR), City of Hope, Dana-Farber/Brigham and Women's Cancer Center, DKMS-Formerly Delete Blood Cancer, Duke Adult Blood and Marrow Transplant Program, Froedtert Hospital and the Medical College of Wisconsin, Henry Ford Transplant Institute, Memorial Sloan-Kettering Cancer Center, Incyte Corporation, Meredith A. Cowden Foundation, Nebraska Medicine, Oregon Health & Science University Knight Cancer Institute, Roswell Park Cancer Institute, Seattle Cancer Care Alliance, Siteman Cancer Center at Barnes-Jewish Hospital/Washington University School of Medicine, Spectrum Health Cancer Center, The Barbara Ann Karmanos Cancer Center, The Leukemia & Lymphoma Society, University Hospitals Seidman Cancer Center, UPMC CancerCenter and Vanderbilt Ingram Cancer Center

We invite you to take our quick survey at the end of this webinar. This will enable us to help future survivors and to continue to develop high quality programs for those we support.

Thank you so much!

Visit us, www.nbmtlink.org